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End-of-life care pathway of head and neck cancer patients: single-institution experience

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Abstract

Background Studies on palliative care of head and neck cancer (HNC) patients are scarce although the affected patient population is quite large.

Objective To evaluate the role of a specialised palliative-care pathway of HNC patients.

Patients and methods Data on all HNC patients who were treated at the Helsinki University Hospital Palliative Care Center during 1 year were retrospectively reviewed. The analysis comprised 60 patients (49 males; mean age 67 years; range 28–88). All patients had a minimum follow-up of 1 year or until death.

Results Fifty-nine (98%) out of the 60 patients died during the follow-up period. Median survival after diagnosis was 11 months (range 3 weeks–11.9 years) and after withholding disease-specific therapies 3 months (range 0–16). Thirty-three (55%) patients received palliative radiotherapy, 27 (45%) had PEG tube and 17 (28%) tracheostomy. Thirty-seven (66%) patients visited an emergency department (ED) (median 1.3 visits; range 0–6) and 21 (35%) were hospitalised at the university hospital during the palliative period. The most common severe complications were infection (also the most common reason for ED visits and hospitalisation), bleeding (four massive airway bleedings with one death), delirium and airway obstruction (one emergency tracheostomy). Twelve (35%) out of the 34 patients who were referred to specialised home care died at home as compared with three (12%) out of the 26 patients not supported by a specialised home-care team.

Conclusions Severe complications leading to an emergency unit visit and hospitalisation are common among HNC patients in their relatively short palliative period reflecting the need for early-integrated palliative care. Collaboration with a specialised palliative home-care team seems to increase end-of-life care at home.

Keywords Head and neck cancer · Palliative care · Terminal care

Heinonen and Loimu contributed equally.

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Introduction

Each year approximately 800 head and neck cancers (HNCs) are diagnosed in Finland. In 2014, 292 of them were registered in the Helsinki University Hospital area with a referral area of 1.9 M [1]. The incidence and survival rates vary according to primary tumour site and stage of the disease [2–4]. Standard treatment for early-stage HNC is either surgery or radiotherapy. In locally advanced diseases, it consists of either definitive chemoradiotherapy, or surgical resection of the primary tumour and neck dissection combined with postoperative radiotherapy.

According to the literature, 5–14% of all patients diagnosed with HNC are offered palliative care without any life-prolonging treatments at first presentation [2–5]. Usually a decision for palliative approach is made due to advanced, either inoperable or metastatic cancer, poor overall health or

other medical conditions that contraindicate cancer-specific treatments. Also, persistent or recurrent tumour growth may show resistance to all available treatment modalities. Overall survival of patients with non-curable HNC is poor, approximately less than 6 months [6, 7].

Palliative care of HNC patients with difficult symptoms, such as airway obstruction, dysphagia, bleeding, malodorous wounds and extreme cachexia, remains a challenge [8–10]. Patients may need a tracheostomy for compromised airway. Cachexia could be a paraneoplastic symptom, but also due to difficult or painful swallowing, and a PEG tube may be needed. Heavy symptom burden, changed body image and impaired physical functioning cause substantial psychosocial distress for the patients and their families [11]. Access to specialised palliative care is needed to ensure good quality of care and a dignified death. Previously published studies among patients with different types of cancer have found that early-integrated palliative care has led to improved quality of life and reduced costs [12–16].

Studies on palliative care of HNC patients are scarce despite the heavy symptom burden experienced by this patient population. Our aim was to describe the current status of palliative care of HNC patients in our university hospital region and to evaluate the specialised palliative care pathway between the Cancer Center Palliative Unit and palliative care providers in primary health care.

Patients and methods

This retrospective study consists of 60 HNC patients in the palliative phase of their disease. The patients were treated at the Center of Palliative Care (Palliative Center) at the Comprehensive Cancer Center of the Helsinki University Hospital (HUU) during a 12-month-period between 1 May 2014 and 30 April 2015. The follow-up period for all patients was 12 months or until death. In this study, palliative phase is defined as a disease period when curative or life-prolonging treatment can no longer be offered. This covered the period from the decision to abstain from cancer-specific treatments (except palliative radiotherapy or surgery for symptom control) to death.

The patients were identified from hospital registries using the International Classification of Disease (ICD-10) coding for carcinoma of tongue, other sites in oral cavity, salivary glands, tonsils, pharynx (C01–C14), sinonasal area, and larynx (C30–C32). Data on patient demographics, tumour characteristics, and previous cancer treatments, as well as data on visits to the Palliative Center or emergency department and hospitalisation periods were recorded from the respective hospital charts. Data on the cause and place of death were collected from death certifications.

An institutional research approval was granted for the study design. Permission to access Finnish Cancer Registry data was granted by the National Institute of Health and Welfare.

Palliative pathway

In Finland, treatment of HNC patients is centralised to the five university hospitals. At our university hospital district, a multi-disciplinary tumour board, including surgeons, medical and radiation oncologists, radiologists, pathologists, palliative-care specialist, and a specialist nurse, is responsible for all primary treatment recommendations.

The palliative pathway of HNC patients in our hospital district was re-organised in March 2014. Since then, all patients with non-curable HNC have been systematically referred to the Palliative Center for specialist-level palliative care. Palliative Center is also responsible for coordination of the care according to a regional palliative-care pathway. The end-of-life care could be provided by a specialised hospice, specialised community hospital wards, general community hospital wards, and home care by specialised or general teams depending on the region. During the data collection time, there were specialised palliative-care services available mainly in larger cities in the HUU region. These included one hospice, two specialised wards and several specialised palliative home-care teams.

Results

Patient demographics and tumour characteristics are presented in Table 1. The mean age of the patients was 67 years, and majority of them were male. Forty-seven (77%) had major comorbidities of which the most common ones were hypertension in 25 (41%) patients, coronary heart disease in 11 (18%), and diabetes in 10 (16%) patients.

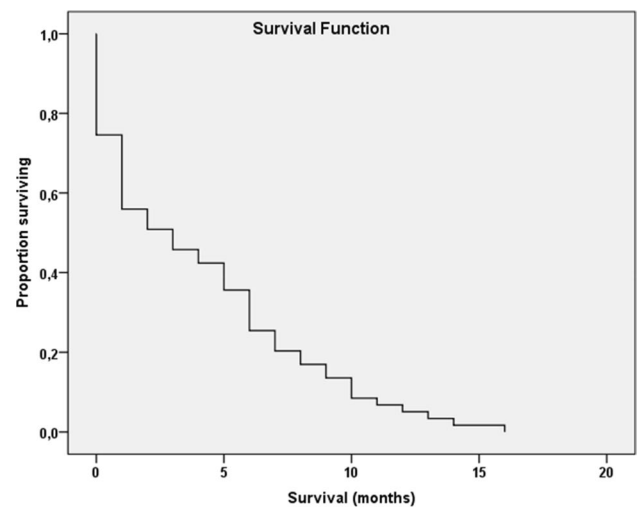
Fourteen (25%) patients had local or locally advanced disease, 16 (26%) had locally recurrent and 30 (49%) metastatic disease. For 25 (42%) of the patients, palliative care was the primary treatment without any previous local or systemic disease-specific treatments.

Palliative period

Median survival after the primary diagnosis was 11 months (range 3 weeks–11.9 years). After referral to the Palliative Center, the median survival was 3 months (range 0–16) (Fig. 1). Thirty-four (56%) of the patients were referred to the Palliative Center by the multi-disciplinary Head and Neck tumour board, 12 (20%) by medical oncologists and six (10%) by radiation oncologists. The remaining patients were referred by other specialist units.

Table 1 Patient characteristics ($n = 60$)

Age years (range)	67 (28–88)
Gender	
Male	49 (82%)
Female	11 (18%)
Place of living during the palliative phase	
Home	51 (85%)
Sheltered home	5 (8%)
Hospital ward	1 (2%)
Other	3 (5%)
Marital status	
Cohabitant	30 (49%)
Single	29 (48%)
Missing data	1 (2%)
Major comorbidities	47 (78%)
Tumour site	
Oropharynx	20 (33%)
Oral cavity	23 (38%)
Salivary gland	3 (5%)
Nasopharynx	2 (3%)
Hypopharynx	4 (7%)
Paranasal sinuses	2 (3%)
Larynx	6 (10%)
Histology	
Squamous cell carcinoma	51 (85%)
Adenoid cystic carcinoma	4 (6%)
Melanoma	1 (2%)
Neuroendocrine carcinoma	1 (2%)
Salivary duct carcinoma	1 (2%)
Unknown	2 (3%)
Stage at diagnosis	
I	1 (2%)
II	6 (10%)
III	5 (8%)
IVA	38 (62%)
IVB	1 (2%)
IVC	8 (13%)
Missing	1 (2%)
Primary treatment	
Surgery	3 (5%)
Surgery and (chemo)radiotherapy	21 (34%)
Definitive (chemo)radiotherapy	10 (17%)
Palliative treatment	26 (43%)
Treatment for local recurrence	
Surgery	6 (38%)
Chemotherapy	2 (12%)
Treatment for metastatic disease	
Chemotherapy	11 (38%)
Palliative treatment	19 (62%)

**Fig. 1** Overall survival from the beginning of palliative treatment decision

Palliative treatment

Palliative treatments are described in Table 2.

Radiotherapy and surgery

None of the patients received palliative surgery during the follow-up period. Twenty-seven (45%) patients had PEG tube and 17 (28%) had tracheostomy.

A total of 33 (55%) patients received palliative radiotherapy. Twenty-four (73%) of these patients received RT

Table 2 Palliative treatment ($n = 60$)

Treatment	N (%)
Palliative RT	33 (55%)
Psychosocial support	4 (7%)
Nutrition counselling	4 (7%)
Physiotherapy	1 (2%)
Medication for symptom control	
Opioids at any phase of palliative treatment	59 (98%)
Long-acting strong opioids	42 (70%)
Laxatives	46 (77%)
Antiemetics	26 (43%)
Benzodiazepines	24 (40%)
Antidepressants	11 (18%)
Tracheostomy	17 (28%)
PEG tube	27 (45%)
Assistive device	23 (38%)
Wheelchair	8 (13%)
Walker	11 (18%)
Bedridden	4 (7%)

to the primary area (primary tumour, local recurrence or locoregional lymph node metastases). Of them, six had received prior RT as a part of the primary treatment with a curative intent. Fourteen (42%) of the 33 patients received palliative RT to distant metastatic sites, such as bone, lungs or thoracic lymph nodes, central nervous system, and subcutaneous or soft tissue metastases.

In the treatment of primary area, conventionally fractionated RT with 30 in 3 Gy daily fractions was used ten times, 20 in 4 Gy daily fractions six times and 15 in 3 Gy daily fractions twice. Three patients received one course of the “quad shot” [17] accelerated palliative RT with 3.5 Gy twice a day for 2 days up to a total dose of 14 Gy. Ten single-fraction courses with either 8 or 6 Gy were given. In addition, despite the palliative intent, two patients received radical RT (one with 66 Gy and one 70 Gy with concomitant weekly cisplatin, both with 2 Gy daily fractions) to the primary tumour area in an attempt to achieve better local control. The distant lesions were treated with 30 in 3 Gy fractions five times, 20 in 4 Gy fractions eight times, 15 in 3 Gy fractions twice, and with a single fraction three times. The mean number of palliative RT courses per patient was 1.4 (range 1–3). Eleven patients received two or more courses of palliative RT to the same site; seven of the re-irradiations were given to the primary tumour area.

Medical treatment

The medical treatments are listed in Table 3. Opioid use increased during the palliative phase: at the entry to the Palliative Center 30% of the patients were using long-acting strong opioids and 32% were using weak opioids. At the last visit to the Palliative Center the corresponding rates were 70 and 8%, respectively. Palliative sedation was performed for one patient.

Complications

Infection was the most common severe complication during the palliative period (24 patients, 40%) followed by bleeding in 11 (18%), delirium in seven (12%), and airway obstructions in five (8%) patients. In addition, there were 12 (20%) cases of other complications including pulmonary embolism and spinal cord compression. Four patients had a massive bleeding from airways and one patient died due to it. One patient received an emergency tracheostomy.

Palliative care pathway

The median number of visits per patient to the Palliative Center was three (range 0–11). In addition, there were a median of three contacts per patient to the Palliative Center by phone (range 0–21).

The total number of visits to emergency units and hospitalisations with the most common reasons are presented in Table 4.

Thirty-four (71%) patients received specialised palliative home care. Twenty-two (65%) of the 34 patients with and 15 (58%) of the 26 patients without specialised home care made at least one visit to an emergency department (ED). The total number of the ED visits for these two groups was 35 and 40, respectively, and the mean number of visits per patient was 1 and 1.5, respectively. The median number of hospitalisations at a university hospital for these two groups was 0.4 (range 0–3) and 0.6 (range 0–4), respectively.

Place of death

Fifty-nine (98%) out of the 60 patients died during the follow-up period. Fifteen patients (25%) died at home, nine patients (15%) died in a hospice, 14 (23%) at a specialised end-of-life care ward in a community hospital, 16 (27%) in a general primary care hospital ward, three (5%) at the university hospital and three (5%) in a nursing home. Twelve (35%) out of the 34 patients who were supported by a specialised

Table 3 Medical treatments

	Entry to the Palliative Centre			Last visit to the Palliative Centre		
	<i>n</i>	Mean dose	Range	<i>n</i>	Mean dose	Range
Strong opioids	18			42		
Oxycodone	9	54 mg/day	10–280 mg/day	16	90 mg/day	10–360 mg/day
Fentanyl (transdermal)	9	72 µ/h	12–300 µ/h	22	68 µ/h	12–300 µ/h
Morphine	0			4	49 mg/day	4–180 mg/day
Weak opioids	19			5		
Codeine	11	38 mg/day	30–120 mg/day	4	30 mg/day	30 mg/day
Tramadol	7	150 mg/day	50–500 mg/day	0		
Buprenorphine (transdermal)	1	20 µ/h	20 µ/h	1	5 µ/h	5 µ/h
Short-acting opioids	18			51		

Table 4 Use of various resources during the palliative period ($n = 60$)

Number of emergency visits	<i>N</i> (%)
0	24 (40%)
1	18 (30%)
2	8 (13%)
3	5 (8%)
4	1 (2%)
5	2 (3%)
6	2 (3%)
Reason for emergency visit	
Infection	12 (22%)
Pain	11 (14%)
Dyspnea	11 (14%)
Coping problem	8 (10%)
Bleeding	5 (6%)
Other	27 (35%)
Number of hospitalisations at university hospital	
0	40 (66%)
1	13 (21%)
2	6 (10%)
3	1 (2%)
4	1 (2%)
5	0
6	0
Reason for hospitalisation	
End-of-life care	0
Infection	9
Coping problem	4
Pain	3
Delirium	1
Bleeding	2
Other	10

home care team, and three (12%) out of the 26 patients without specialised home care died at home. There was no difference in the number of deaths at home between single-living and cohabitant patients.

Discussion

End-stage HNCs are characterised by heavy symptom burden and short life expectancy. The symptoms related to locoregional tumour growth impact essential human functions such as breathing, speaking, eating and swallowing. Facial mutilation as a result of tumour growth, local treatment or both can cause major functional disability and have a negative impact on the integrity of body image [18]. Difficult physical symptoms and disfigurement cause enormous psychological distress not only to patients but also to their families and caregivers [19]. This emphasises the

importance of a specialised, well-organised palliative-care pathway.

Majority of HNC patients are diagnosed at an advanced stage when treatment options are limited and thus, their prognosis in general remains poor. In the present study, three quarters (77%) of patients had a locally advanced or metastatic disease. More than every third patient (42%) was referred to the Palliative Center at first presentation of the disease; this represents 9% of the newly diagnosed patients during that year in this university hospital region [1]. This proportion is comparable to the previous nationwide studies performed in Finland [2–5].

Overall survival in the present cohort was relatively short with a median of 11 months after primary diagnosis and only 3 months after the decision of withholding cancer-specific treatments. Previous retrospective studies [6, 7] have reported similarly short survival rates, with certain factors, such as disease stage, primary tumour location, palliative interventions, patient performance status, and comorbidity, having an impact on the prognosis. In their study of 808 HNC patients without cancer specific treatments, Kowalski et al. [6] reported a 3.8 months median overall survival, whereas Ledebøer et al. [7] reported that the median length of the palliative period was 5.3 months.

Over half the patients received palliative RT, and one-third of them went through at least two courses of RT during follow-up. Palliative RT was given in most cases to the head and neck area; either due to locoregional recurrence after curative-intended primary treatment, or symptomatic locoregional tumour growth in a primarily incurable disease. The most common RT dose to the primary area was 30 with 3 Gy daily fractions. In addition to locoregional radiotherapy, a quarter of the patients received palliative radiotherapy to various distant lesions, most of which were uncomplicated bone metastases or metastases in the thoracic area. These were typically treated with single fractions or short fractionated courses.

Although there is evidence that locoregional palliative treatments are beneficial for patients with non-curable locally advanced HNC [20], there is still no clear consensus on the optimal scheduling of palliative RT for these patients. Short hypofractionated courses of palliative RT are supported by several prospective [17, 21, 22] and retrospective [23–26] studies demonstrating both good tolerability and symptom control in this population with a very limited life expectancy. The high number of palliative locoregional re-irradiations in our patient cohort emphasises the need for further investigations to determine the optimal palliative RT protocol for these patients.

There were a limited number of severe local complications among this highly symptomatic patient group, suggesting that elective procedures to avoid major complications were successfully used. Likewise, locoregional

complications were rarely the reason for ED visits or hospitalisations. Percutaneous nutrition and prophylactic tracheostomy were widely used among our patients, and only one patient needed an emergency tracheostomy. The use of strong opioids was common, and the number of opioid users, as well as the opioid doses, increased significantly during the follow-up.

However, although most patients had a round-the-clock access to specialised palliative care services, a relatively large proportion of the patients did visit an ED (66%) or got hospitalised in a university hospital (35%) during the last months of their lives. The leading causes of ED visits and hospitalisations were infections, pain, dyspnoea, and coping difficulties. For comparison, in a small retrospective study on 32 patients with HNC [8], bleeding was the most common reason for visiting an emergency unit, followed by pain, respiratory symptoms and swallowing problems. Some of the emergency visits and hospitalisations in our patient cohort would likely have been avoidable. This further emphasises the need for more intense follow-up of these patients.

According to a European study [27], 60% of people would prefer dying at home. A recent Cochrane review [28] reported that home-based end-of-life care services increase the likelihood of home deaths. In accordance with the Cochrane review, also in our cohort an access to specialised palliative home care seemed to increase the home-death rates (35% of the patients with specialised home care vs. 11% without it), but still, even with the support of specialised palliative home care, only one-third of the deaths in our cohort did occur at home. These low home-death rates could partly be explained by the significant symptom burden, high rate of infections and the fact that half the patients were living alone, even though no difference in the rate of home deaths was found between the single-living and cohabitant patients. Further, the patients with a specialised palliative home care have a direct access to community hospital palliative wards whenever needed. Since some of the difficult symptoms may be easier to manage at a hospital ward, this could have further reduced the home-death rates in this cohort.

There were some limitations in this study that should be pointed out. First, this was a small retrospective study, which limits further statistical analysis and makes this report a descriptive one. Second, the symptoms and their development were not systematically reported in the patient records. Strength of this study is its population-based nature as all palliative-phase HNC patients in this university hospital region during one year were included. This area represents almost one-third of the Finnish population and there are no reasons to expect that the present series would differ from those in other regions in Finland.

In conclusion, a systematic collaboration with a Palliative Care Unit seems to assure sufficient end-of-life care to HNC

patients with non-curable disease. Specialised palliative care pathway, particularly home care, increases the possibility for end-of-life care at home. Due to heavy symptom burden and short life expectancy in this patient population it is obvious that intense palliative care pathway from Cancer Center to home care is needed to ensure good quality of palliative care and a dignified death.

Compliance with ethical standards

Funding This study was funded by the Helsinki University Hospital Research Fund (Grant number TYH2015204).

Conflict of interest All authors declare no conflict of interest.

Ethical approval All procedures performed in this study involving human participants were in accordance with the ethical standards of the institutional research ethics committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. This is a retrospective chart review and thus, no approval by the Research Ethics Committee was needed according to Finnish Law. An institutional research permission was granted.

Informed consent This is a retrospective chart review and thus, no informed consent was needed according to the Finnish Law (and all patients were dead at the time of the study).

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